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BURDEN OF INFORMAL CARERS OF MENTALLY INFIRM ELDERY IN LANCASHIRE

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## BURDEN OF INFORMAL CARERS OF MENTALLY INFIRM ELDERY IN LANCASHIRE

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# **ABSTRACT**

Objectives: To compare the burden of supporting demented and non-demented mentally infirm elders in an English community; determine the prevalence of emotional distress in carers and to investigate the relationship between carer well being and duration of care giving.

Design: Cross-sectional study of informal carers of the elderly referred to a psychogeriatric service, using a questionnaire investigating carer socio-demography, carer-dependent interpersonal relationship in relation to care giving and care-recipient dependency needs using a modified version of the CADI; and, the 28-item GHQ.

Setting: Lancashire communities of Fleetwood, Thornton-Cleveleys, Poulton- Le-Fylde and Over-Wyre.

Results: Ninety one (72%) carers of the elderly mentally infirm participated in the study. Carers (n = 48) of the demented experienced significantly more burden, including psychological and physical health problems than carers (n = 43) of the non-demented (P = 0.001). The prevalence of emotional distress in all carers was 42% (dementia supporters = 56%, non-dementia supporters = 26%). Emotional distress in supporters was directly related to the degree of difficulties (particularly lack of private time, loss of control in caregiving tasks, patient behavioural problems) experienced in care giving, and, the degree of patient dependency needs. Carer/patient interpersonal relationship tended to worsen as care giving progressed; however, no significant association was established between duration of care and emotional distress in carers. Out of 51 carers receiving respite admission services, six (12%) considered such admissions as additional burden.

Conclusions: Carer burden, including psychological and physical health concerns, was comparatively greater in carers of the demented than in carers of the non-demented. Respite care services although beneficial to most care givers, may constitute further burden to some. Factors accounting for these observations are explained. To ameliorate carer burden, measures enabling greater availability of private time, and, improving care giving skills, should be encouraged.

### INTRODUCTION

Many carers are under significant degrees of burden. Caregiver burden refers to the physical and psycho-social difficulties experienced by carers. It is unclear who is at the most risk from adverse consequences and which aspects of caring are most stressful. Some studies suggest that the carers' social life is most affected(1-2), while others suggest emotional difficulties (anger, depression, guilt, etc) as most affected(3-4). There appears to be no clear and consistent relationship between the nature and extent of disability, the duration of care giving and the degree of carer burden(5-6). Carer's subjective perceptions, rather than objective criteria, have been considered more important in determining carer burden(6-7).

To ensure continuity of care in the community, carers require the support of the formal services. However due to limited formal care resources, there

is need to determine which carers require greater service provision. This can be achieved through the comparative investigation of the burden of supporting different groups of care recipients; results of which may result in the prioritisation of services supporting carers and dependants facing difficulties in the care giving situation. The number of studies comparing the burden of supporting different groups of elderly mentally infirm is limited(8-9).

The relationship between carer distress and duration of care has been little investigated(5). The degree of emotional distress in carers may be directly(10) or inversely related to duration of care(11); some studies reveal no relationship between these variables(12). The correct timing of formal care interventions may be informed by knowledge on the relationship between carer well being and duration of care-giving.

The objectives of the study were: (i) to conduct

a comparative investigation of the burden of supporting the demented and non-demented mentally infirm elderly (ii) to determine the prevalence of emotional distress in these different carer samples and (iii) to investigate the relationship between carer wellbeing and the duration of care. The specific hypotheses tested include: (i) carer burden is significantly greater in dementia supporters than in non-dementia supporters, (ii) carer emotional distress is directly related to the burden of care and (iii) there is a direct relationship between carer distress (emotional) and duration of care.

# MATERIALS AND METHODS

Subjects were informal carers of elderly mentally infirm receiving psychiatric care at Fleetwood Hospital, Fleetwood, Lancashire. Informal carers were defined as assisting the patient with shopping, domestic chores, personal care and facilitation/supervision of the patient's compliance with care plan. One hundred and ninety six patients were referred to the service between January 1995 – January 1998 of which, 127 had informal carers. Ninety one (72%) informal carers consented interview.

Carers' demography (age, sex, marital status, occupation, relationship to the dependant, living situation: co-residency or otherwise with care recipient) were accessed. The relationship between carer emotional wellbeing and duration of care was investigated. The quality of carer dependant relationship prior to care giving and at the time of the study were determined. The benefit to the carer of previous care recipient formal placements (nursing or residential unit) was investigated.

Patients dependency profile was constructed by determining: (i) frequency with which care/supervision was provided by carer and (ii) extent of help required (no help, help needed with part of activity, help needed with all of activity) by the patient with regards to activities of daily living: washing, dressing, feeding, toiletting, walking, bathing, and household tasks. Patients' psychomotor activities were evaluated: wandering behaviour, confusion, socially unacceptable behaviour, agitation, uncooperativeness and difficulty holding normal conversation. The dependency profile had a maximum score of 58 (scores converted to percentages).

Carer burden was determined using the Carers' Assessment of Difficulties Index (CADI) (13): Pilot study indicated carers had difficulty in completing the CADI in its original format, so it was modified in to a "Yes" (= 1 point) or "No" (= 0 point) format. The CADI provides an overall summary score and describes the prevalence of, and, perceived stressfulness of individual care difficulties. The original CADI had 30 items, to which were added two items investigating effect of care giving on work and marital relationship respectively, giving a total modified CADI score of 32. Carer emotional distress was determined using the 28-item General Health Questionnaire(14). A score > 4/5(15-16), indicated carer emotional distress. For qualitative analysis, the total GHQ-28 scores were recorded using the 'GHQ scoring' method.

Psychiatric diagnoses(17) were assigned on the basis of clinical history, mental and physical states examination and review of case notes.

The Blackpool, Wyre and Fylde Research Ethics Committee, granted ethical approval for the conduct of the study.

Statistical Analysis: Data were analysed manually and presented descriptively. The Statistical Package for Social Sciences (SPSS) for windows version 6.1 was used in analysing relevant data. Normally distributed data in demented and non-demented groups were assessed with the student's t-test, non-normally distributed data with the Mann-Whitney U test, and categorical data with Chi-square test. Spearman correlation was used for non-normally distributed data.

#### RESULTS

There were 47 male and 44 female carers, with a mean (S.D) age of 66.2 (11.7) years (range 34-88 years). Carer age groups were: 21-40 years 3%; 41-60 years, 8%; 61-70 years, 22%; 71-80 years, 45%; 81-95 years, 3%. Sixty-four (70%) carers were spouses (husbands=36, wives=28). Twenty three (25%) carers were care-recipients' off springs (sons=9, daughters=14). Other carers: brother, 1; sister, 1. daughter-in-law, 1; and, neighbour, 1. Seventy five (81%) carers were coresident, while 16 (19%) lived away (< 1 mile=12; >1 mile=4). All carers and their dependants were English. Twelve (13%) cares were employed. Carer education: primary 13(14%), secondary 48(53%), post-secondary, 12 (13%), and, vocational, 18(20%). Eighty four (92%) carers were Christian, and, 7(8%) had no religious affiliation. The mean (S.D) duration of care giving was 82.4 (59.5) months (range 6-540 months).

Twenty carers were married to partners other than the patient at the time of the study, 17(85%) described their non-patient partners as supportive in the care giving role, with no adverse effect on marital relationship. Regarding spousal carers, 37(58%) reported satisfactory relationship with the dependant, while 26 reported unsatisfactory relationship (loss of physical and emotional relationship), particularly, with deterioration in patient's mental state. Employed carers (n=12) reported work problems. Seven out of 79 unemployed carers gave up work for care giving.

Characteristics of care recipients, and Care recipient dependency: There were 91 care recipients (male = 34; female = 57), with a mean (s.d) age of 73.3 (7.2) (range 53-90) years. Out of 16 patients not co-resident with their carers, 14 lived alone, while two lived with their spouses (who due to advanced age, could not provide care). Patients' diagnoses were: dementia 48(53%); affective disorder, 32 (35%); delusional disorders, six (7%); anxiety disorders four (4%); and alcohol dependency one (1%). The mean duration of contact with psychogeriatric services was 20.0 (11.2) (range 3-48) months. There were no significant differences between patients and carers in terms of age, education, occupation (employed or unemployed) and residential status.

Demented patients, compared with the non-demented, were more dependent on their supporters; the mean (S.D) dependency profile rating score of demented and non-demented patients was 51(15.4) and 28.8 (12.5) respectively (Mean diff=23.0, 95% Cl 17.1, 28.9, t=7.8, df=89.0, p<0.001).

Carer-dependant inter-personal relationship: Prior to caregiving, 82 carers had satisfactory (excellent 35, very good=37, good=10) relationship with the patient, while nine carers had unsatisfactory relationship with the patient. With progression of care giving, the carer/dependant relationship altered, with 61 reporting it as satisfactory and 30 describing it as unsatisfactory. Six (7%) carers reported improved relationship with carerecipient. Responding to the CADI, the deterioration in carer-dependant relationship was significantly greater in dementia supporters 20(41.7%) than in non-dementia supporters 9(20.9%). Similarly, significantly more dementia supporters (24, 50.0%) felt angry about the care giving situation than their non-dementia supporting counterparts (8,18.6%).

Previous admissions into formal care and care giver burden: Fifty one carers (56%) had dependants admitted into formal care during illness, 45(88%) considered these admissions as relieving care giving burden. Six (12%) carers, considered such admissions as additional burden (due to need for regular visits to the hospital, and, performing other duties to the patient while in formal placement).

Distribution of carers according to CADI item categories/GHQ response: CADI items were

categorised (Table 1) into: lack of private time; loss of control in caregiving; social difficulties/limitation of social involvement; family and marital problems; impaired carer/patient relationship; patient behavioural problems; physical health problems; and, psychological health difficulties. The mean (s,d) CADI score for dementia supporters was 16.4 (6.3), while that for non dementia supporters was 9.0 (7.2); mean difference=7.4, 95% C.1 4.6; 102; t=5.21, df=89, P=0.001. Responding to CADI items relating to physical well being, 47(52%) carers were physically unwell, and, responding to CADI items relating to emotional well-being, 45 (49.5%) carers were emotionally unwell (Table 1). Responding to the GHQ, 27 (56%) dementia caregivers, and 11 (26%) non-dementia supporters, were emotionally distressed. The overall psychological distress rate was 42%.

### STATISTICAL ANALYSIS

Hypothesis i: Informal carers of the demented, compared with carers of the non-demented, experience greater degree of burden and emotional distress.

Table 1

Distribution of caregivers according to CADI items categories

CADI Items Category	Total Yes (n=91) Response %	Dementia (%) (n=48)	Non Dementia (%) (n=43)
Lack of private time	48(52.3)	36(75)	12(27.9)
2. Loss of control in caregiving	46(50.5)	34(70.8)	12 (27.9)
3. Social difficulties/			
Limitation in Social involvement	45(50)	29(60.4)	16(37.2)
4. Family and/or marital difficulties	39(42.9)	26(54.2)	12(27.9)
5. Impaired carer/	39(42.9)	29(60.4)	10(25.6)
dependant relationship			
6. Patient behavioural problems			
(immobility, excessive need for	42(46.1)	29(60.4)	14(32.5)
personal care, embarrassing			
behaviour, agitation)			
7. Physical health problems (physical			
exhaustion, malaise)	47(51.6)	36(75)	11(25.6)
8. Psychological health			
Problems (insomnia, anger,	45(49.5)	29(60.4)	16(37.2)
depression, worry, guilt)			

Table IIa

Carer-burden/dependency profile and GHQ overall/subscale scores in carers

,	Dementia (n=48)	Non-Dementia (n=43)	Statistics
Mean (sd) CADI (max score =32)	16.4(6.3)	9.0(7.2)	Mean difference 7.4 (95% Cl 4.6, 10.2) t=5.21, df=89.0, p=0.001*
Median (IQR) GHQ- 28, non-Likert	6.0 (2, 10.8)	1.0(0,4.5)	Mann-Whitney U=631, W=1577**, Z=3.23, p=0.0012)
GHQ-28 cases (cut-off 4/5)	27(56%)	11(26%)	X <sup>2</sup> =8.77, df=1, p=0.0031
Mean (sd) GHQ-28, Likert	24.6(12.3)	17.3(9.9)	Mean difference 7.3 (16, 12.0) T=3.13, df=88.0, p=0.002
Median (IQR) GHQ-28 anxiety	6.0(4,10)	4.0(1,6)	Mann-Whitney U=595, W=1541, Z=3.49, p=0.001
GHQ-28 depression Median (IQR)	2.0(0,4.8)	0(0,2)	Mann-Whitney U=739, WA=1685, Z=2.46, p=0.014
GHQ-28 social dysfunction Median (IQR)	7.0(7,10)	7.0(7,9)	Mann-Whitney U=884, WA=1830, Z=1.21, p=0.22
GHQ-28 somatic Median (IQR)	6.0(3, 10)	3.0(1, 5)	Mann-Whitney U=647, WA=1593, Z=3.08, p=0.0021
Dependency Mean (sd)	51.9(15.4)	28.8(12.5)	Mean Diff=23.0 (95% Cl 17.1, 28.9), t=7.78,df=89.0, p<0.001

Note IQR = Interquartile range

The mean CADI scores for dementia and non-dementia supporters, were 16.4 and 9.0 respectively-difference of which was statistically significant (mean difference 7.4, 95% Cl 4.6, 10.2, t=5.21, df=89, p=0.001).

Conclusion: Carers of the demented, compared to carers of the non-demented, experience significantly more burden, including emotional distress (total GHQ-28 score, anxiety, depression and somatic concern).

Hypothesis ii: Emotional distress in carers is directly related to the burden of care

- 1. GHQ score versus CADI score for all carers, Spearman rank correlation: r=0.56, P<0.001.
- 2 GHQ score vs CADI score for dementia supporters, r=0.53, p<0.001

3 GHQ score vs CADI score for non-dementia supporters r=0.65, p<0.001 (n=43)

Carer emotional distress is directly related to the burden (difficulties) encountered in caregiving, in all carers, and separately in both carers of demented and non-demented patients.

Hypothesis iii: The degree of carer distress is directly related to the duration of care. Duration of care in years vs GHQ-28 score: Spearman rank corelation: r=0.052, p=0.625, there is no relationship of statistical significance between duration of care and overall psychopathology.

Correlation analysis in respect of hypotheses ii and iii is represented in Table IIIa.

<sup>\*</sup>Independent t-test and main difference between dementia and non-dementia groups with 95% confidence intervals for difference.

<sup>\*\*</sup>Mann-Whitney U-test (non-normally distributed data).

Table IIb

GHQ cases vs Mean CADI scores: Test of significance of the difference of means.

	GHQ 'Caseness'		Mean CADI (S.D)		Statistics
	Yes	No	GHQ cases	GHQ non-cases	
All carers	38	53	17.8(6.3)	9.4(6.6)	Mean diff=8.4, (95% C.I 5.6, 11.1) p<0.001
Dementia carers	27	21	18.4(6.0)	13.8(5.7)	Mean diff=4.6(95% C.I 1.1, 8.0) p=0.011
Non-dementia carers	11	32	16.3(6.9)	6.6(5.5)	Mean diff=9.8 (95% CI 5.6, 13.9) p=<0.001

Table IIIa

Correlation analysis-GHQ scores in relation to CADI scores and duration of care

	GHQ vs CADI	GHQ vs Duration of Care	
All carers	R=0.56, p<0.001+	r=0.052, p=0.625*	
Dementia carers	R=0.53, p<0.001	r=0.08, p=0.60*	
Non-dementia carers	R=0.65, p<0.001+	R=0.18, p=0.24*	

<sup>+=</sup>Statistically significant, \*=Not statistically significant

Table IIIb

GHQ vs duration of care: Mann-Whitney statistics

	GHQ'caseness'		Statistics	
	Yes	No		
All carers	38	53	U=922, W=1833	
			Z=0.69, P=0.49*	
Dementia carers	27	21	U=264, W=495	
			Z=0.41, P=0.68*	
Non-dementia carers	11	32	U=163, W=229	
			Z=0.36, P=0.72*	

<sup>\*=</sup>Not Significant

There is no evidence to support the hypothesis that the degree of emotional distress in carers is directly related to the duration of care.

### DISCUSSION

The main strength of the study, was the use of an epidemiologically representative sample of consecutive referrals to a psychogeriatric service. Also, conducting interviews in care-recipient's homes enabled first hand assessment of their dependency needs. Weaknesses of the study include the small sample size, which limits generalisation of the findings and failure to apply rigorous research criteria in establishing clinical diagnosis of the dependants. However, the results may find application in routine clinical service, since diagnoses were made using normal clinical process in routine psychiatric care.

It is noteworthy that difficulties with family and marital life was reported by 39(43%) carers (Table 1), particularly, carers of the demented. Additionally, 26(41%) spousal care givers had marital difficulties. The demands of caring for parents can impinge on time available for fulfilling responsibilities to children and spouses, resulting in impaired family well being and early institutionalisation(1,18). Difficulties with family and marital well being, as observed in this study, underscores the need for investigating family well being during

routine psycho-geriatric assessments. Families experiencing difficulties with care giving may be assisted thus, prolonging community care.

The conceptual framework of the CADI is similar to the Zarit et al (7) Carer Burden Index, which reflects various definitions of care giver burden: the effects of patient's illness on the family, such as physical, emotional and social problems. The significant difference in mean burden (CADI) scores (Table IIa) for dementia and non-dementia supporters was accounted for by CADI items: carer having insufficient private time, patient behavioural problems/excessive demands for personal care, carer feeling helpless/not in control of the situation, strained family relationships, limitation of social life, sleep difficulties, emotional (anger/guilt/ worry/depression), and, physical health difficulties (exhaustion and malaise). The significant difference in the mean CADI scores for carers of the demented and non-demented, confirms this study's first hypothesis.

Some carers (n=33 37%), particularly carers of the demented, did not receive family support/visits respectively. A consistent theme by carers, is a sense of isolation and inability to share care giving tasks with relatives (19). Family support ameliorates carer burden, and facilitates efforts of the formal elder-care services(20-21). Thus, the improvement of impaired family support network, is an important step in relieving carer distress.

Forty five (88%) carers considered respite placement of their dependants, as relieving care giving burden; on the other hand six (12%) carers considered such placements as additional burden, due to need to visit patients regularly. Care givers, particularly elderly ones, found such visits exhausting. Also, the need to attend to the material needs of the patient while in formal placement constituted additional burden to some care-givers. That some carers found respite placements as burdensome, is at variance with the view that such placements, by providing emotional and physical rest, are beneficial to care givers(22). Indeed, Worcester and Hendrick(23) have noted that carers' evaluations of respite care are not always positive. To relieve carers of the burden of respite placements, such services may have to be in the carers' own homes, thus allowing them needed holiday. Where formal/respite placement of the patient is mandatory, carers may be encouraged to pay minimum number of visits to the patient, without feeling guilty about this.

A substantial proportion(38%) of carers thought professional workers don't seem to appreciate the problems carers face' (CADI item 7). Such views, which achieved a high degree of factor loading on factor analysis of the CADI (13), have significant implication on carers' ability to cooperate with the formal services. Carers who believe that professional workers lack understanding of their difficulties may, at risk to their health, fail to express their concerns and

seek support when care giving becomes overwhelming(24). Routine exploration of care giver burden during psychogeriatric assessments would help in developing informal carer confidence in the formal care services. This view is supported by the observation that most carers, following opportunity to express their concerns, experienced a sense of relieve and willingness to seek the assistance of formal elder-care services.

Carers' physical health may be assessed from subjective reports or from indirect estimates. The former approach adopted in this study indicated 47 (51.6%) carers as physically unwell (CADI item: my physical health suffers). Analysis of the variable 'my physical health suffers', based on carer groups, showed 36(75%) dementia caregivers as physically unwell, as against 11(26%) non-dementia supporters. This significant difference in observation may be a function of the greater burden experienced in supporting the demented compared to the non-demented. Indeed, Wijeratne (25), has observed that poor physical health in carers, is a function of their burden.

Poor physical health, a major sequelae of care giving, significantly predicts carer emotional distress (26). The advanced age of most carers and/or the chronic stress associated with long-term care giving, may predispose carers to poor physical health(27-28). Carers' ability to continue with care in the community depends on their physical health(26). Therefore, to prolong care in the community, routine investigation of carer health should be done with a view to identifying and supporting carers with health difficulties.

Forty seven (51.6%) carers rated themselves emotionally distressed when responding to the CADI item: 'my emotional well-being suffers'. To test hypothesis (i) in this study, scores on this item were evaluated, based on carer grouping. There was significant difference in the scores of both groups of carers: 31(65%) dementia supporters were emotionally unwell, compared to 16(37%) non-dementia supporters. This significant difference in perceived emotional distress in both carer groups was confirmed on assessment of GHQ responses: 56% 'caseness' for dementia supporters vs 26% 'caseness' for non-dementia supporters ( $X^2=8.77$ , d.f=1, p=0.0031, statistically significant). These findings, confirming hypothesis one in this study, are in conformity with those in an earlier study(29), in which carers of the demented, compared with other carers (and the general population), had significantly higher rates of health (physical and emotional) problems. Eagles et al(8) have contrary to observations in this study, found no significant difference in rates of psychiatric morbidity between carers of the demented, and nondemented.

The significantly high number of GHQ 'cases' (n=38 (42%)), scores weighing predominantly in the anxiety, depression, and, somatic sub-scales), is in conformity with the high rates of emotional distress

observed amongst carers in previous studies(15-16). The high levels of dysphoria in these carers, supports the view that clinics for the impaired and their families should be an integral part of the psychogaeriatric service(30). In such clinics, care givers facing difficulties may be supported by way of care giving skills training, counselling, and psychotherapy(31-32).

Several reasons may account for the higher risk/ rate of dysphoria in dementia supporters compared with non-dementia supporters. Cognitive deficits, particularly in the demented may impair appreciation/ reciprocation of carer support (scores on the CADI item: 'the person I care for does not always appreciate what I do' were significantly greater in dementia supporters than in non-dementia supporters), thus hindering adequate emotional contact between them. Also, caring for the demented, in comparison with the non-demented, involves dealing continually, with difficult and challenging behaviour, resulting in emotional distress for the unprepared. Problems such as insufficient private time, physical exhaustion, feelings of anger, self-doubt, frustration and helplessness, work problems, family/social alienation, and social embarrassment, which carers of the demented may experience more frequently than other carers, may result in higher rates of dysphoria in them.

Dementia and non-dementia supporters' attributions of illness severity and perception of patient's prognosis may account for the significant difference in rates of dysphoria between them. Impairments in activities of daily living, particularly in the demented, may be more distressing to care givers because they reflect more severe and possibly irreversible disability. Care givers may perceive depression or neuroses as reversible and less critical. Also, it may be that non-demented patients by being less physically demanding are easier to care for, thus evoking less distress in their supporters.

In conclusion, there is significant difference in the degree of burden associated with supporting the demented and non-demented respectively. While subjective appraisals may be significant in determining carer burden, objective factors-measured by carerecipient dependency needs (greater in the demented than the non-demented), are also significant in predicting carer burden. Thus, from a service provision perspective, carers of the demented may require greater allocation of formal support resources, than their non-dementia supporting counterparts. The presence of positive, though insignificant, rather than negative correlation between carer distress and duration of care, suggests direct relationship between these variables; the study of a large sample size would help clarify this. It is possible that the adverse patient/supporter relationship observed in the study, may precipitate, and, maintain, emotional distress in carers. The timing of formal service intervention(s), is best informed, by careful monitoring over time, of each carer/patient dyad.

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